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# Applying human rights to children's<sup>1</sup> participation in research

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## Abstract

How can ideas and concepts from human rights inform and challenge ways of undertaking research with children? Over the last twenty years, there has been a significant 'turn' in the social sciences and related disciplines, to undertaking research *with* rather than research *on* children. This turn has several strands: developing 'participative' or 'creative' methodologies to work directly with children; an intense and extensive focus on ethics; expanding the ways children can be involved in research, from participants to advisers, experts and researchers; and a research objective to present children's 'voice'. This chapter will examine such strands, to consider current challenges and tensions, utilising ideas and concepts from human rights. In particular, it will consider how the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities can challenge conceptualisations of capacity and competence, communication and voice, and research ethics.

## Introduction

Over the last twenty years, there has been a significant 'turn' in the social sciences and related disciplines, to undertaking research *with* rather than *on* children. Whereas in the past adults were often treated as informants on behalf of children, researchers increasingly recognise that children can respond and participate on their own behalf and provide meaningful contributions to address the research questions. Whereas formerly children were the objects of research ethics, childhood researchers firmly assert that children should be able to agree in their own right to their research participation. Research itself is no longer the sole preserve of adults; children themselves are increasingly taking on different roles within research processes, from advising research studies as consultants, to peer researchers collecting and analysing data, to co-producing projects with adults (Bradbury-Jones and Taylor 2015; Davis 2009). This change to research with children, rather than on

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<sup>1</sup> This chapter uses the 'term' children, as the book overall is focusing on younger children. The CRC itself defines a child as 'every human being below the age of eighteen years unless, under the law applicable to the child, majority is obtained earlier' (Article 1).

children, has thus created new opportunities and challenges for research methods, governance, procedures and ethics.

At least one inspiration for this change is the international recognition of children's human rights. In 1989, the UN General Assembly ratified the United Nations Convention on the Rights of the Child (CRC). It is now the most ratified international human rights treaty ever (all States Parties have ratified it except the USA). With ratification, States Parties have a duty to implement the CRC provisions. The CRC is an extensive document of 54 articles, covering all types of human rights from civil to economic to cultural, and has three additional Optional Protocols.<sup>2</sup> CRC's participation rights have been particularly influential because they challenge traditional conceptualisations of childhood as merely passive recipients of services and solely vulnerable dependents on their parents, families and communities. Children have the right to have their views duly considered in all matters affecting the child. More recently, this right to participation was re-articulated in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (2006), in Article 7. Children's participation is firmly on the human rights agenda internationally.

This chapter will explore the implications of human rights, and particularly of the CRC and CRPD, for research with children. First, it provides an overview of the human rights framework and its potential applications to research. Then the chapter explores three themes, which are particularly enhanced and/or challenged by human rights: a reconsideration of communication and 'voice'; pervasive concepts of capacity and competence; and research ethics. The chapter concludes by outlining how a human rights approach continues to challenge research with children.

## Human rights framework: potential applications to research

Human rights are recognised for all people, simply on the basis of their being human. These rights are inalienable – they cannot be given away or abrogated; they are universal – they apply to all people in all countries in all contexts; and human rights must be addressed holistically – the range of human rights must be realised, rather than prioritising one and not addressing others. Such ideas are both powerful and controversial. Rights can be variously defined and conceptualised but core to

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<sup>2</sup> Optional Protocol to the Convention on the Rights of the Child on the sale of children, child prostitution and child pornography; Optional Protocol to the Convention on the Rights of the Child on the involvement of children in armed conflict; Optional Protocol to the Convention on the Rights of the Child on a communications procedure.

virtually all human rights theories are requirements for duty-bearers to recognise and realise the rights of the rights-holders (e.g. see Jones 1994; Mahoney 2007). There are requirements therefore both for duty bearers' accountability and for rights holders' access to redress if their rights were not upheld. It is these elements that distinguish a rights framework from other popular ones, such as wellbeing (Bradshaw 2014; Camfield et al. 2009) or vulnerability (Fineman 2013; Herring 2012). Rights fundamentally respect a person's dignity. They are important 'moral coinage' (Freeman 1983: 2) as well as having political and legal power. Rights are described as political 'trump cards' by Dworkin (1997: xi), as so fundamental they cannot be politically compromised (although in practice they may well be). Human rights basis in international law gives them political 'stickiness': while laws can be changed, this typically takes time and a certain amount of consensual agreement. Thus rights recognised in law are less quickly and easily changed than other areas of policy, such as the definitions of 'wellbeing' or a charitable concern for vulnerable children. Applying a human rights framework to children, people with disabilities, and children with disabilities, thus powerfully asserts their human dignity and value, shines a light on discrimination against them, and thus can change how individuals and society perceive them.

Human rights are not without their critics, however, both conceptually and in practice. Conceptually, rights have been roundly criticised for being based on a false premise of the autonomous rational individual. Instead, critics (e.g. Arneil 2002; Sandel 1992) suggest that people are inherently social, no one is autonomous and rationality is not a necessary criterion to have rights. King (1997) is provocative, in suggesting that a rights framework for children narrows the focus, away from fundamental issues of war, national disasters and global capitalism, which are not or inadequately addressed by human rights yet have the greatest impacts on children's lives worldwide. In practice, human rights face a strong critique about their universal application, as being culturally inappropriate in many parts of the world and merely the latest version of colonialism and the Global North's imposition on the Global South (e.g. Valentin and Meinert 2009). States Parties may ratify the conventions but implementation remains varied and accountability procedures at an international level are relatively weak (Alston and Crawford 2000). Thus, there are potential drawbacks of a human rights approach, in recognising relationships, cultures, and addressing wider social issues.

All human rights treaties apply to children with disabilities. This chapter considers the ones particular to children and to people with disabilities. The creation of both the CRC and CRPD were contentious in themselves – why is a separate convention required for children, or for people with disabilities, when they are already included within other human rights treaties? But the arguments

were made that specific attention needed to be focused on these groups, to ensure their particular rights were articulated and recognised (see Hanson 2014; Kanter 2015).

The CRC has four general principles (UN Committee on the Rights of the Child 2003): Article 2 (non-discrimination); Article 3(1) (a child's best interests must be a primary consideration in all actions concerning children); Article 4 (inherent right to life, survival and development) and Article 12(1) on children's views. Article 12 is but one of the participation rights within the CRC, which includes Article 13 (freedom of expression), Article 14 (freedom of thought, conscience and religion), Article 15 (freedom of association and peaceful assembly) and Article 17 (access to information). But it is Article 12(1) that is the most cited for encouraging children's participation, and the one often viewed as transformative and radical for children and childhood (Holzscheiter 2010; Reid 1994). Article 12(1)'s precise wording is:

States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

Article 12 must be applied widely, with a broad understanding of 'all matters affecting the child' (UN Committee on the Rights of the Child 2009: para 26-27). This is elaborated upon for young children, as needing to be:

... anchored in the child's daily life at home (including, when applicable, the extended family) and in his or her community; within the full range of early childhood health, care and education facilities, as well as in legal proceedings; and in the development of policies and services, including through research and consultations. (2005: para 14)

Children's views must also be considered seriously (UN Committee on the Rights of the Child 2009: para 28). In summary, then, the UN Committee on the Rights of the Child underlines the considerable responsibility of families, professionals and others to support young children in their rights to participate. Participation must be part of young children's daily lives.

Article 23 of the CRC particularly addresses the rights of disabled children. The Article is lengthy, starting with the recognition that a disabled child 'should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community' (Article 23(1)). Subsequent sub-sections address disabled children's right to special care, resources and affordable assistance across a range of services, and international exchange of information.

The CRPD is composed of 50 articles.<sup>3</sup> Article 7 is dedicated to children with disabilities:

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<sup>3</sup> The CRPD also has an Optional Protocol on communications.

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.
3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

These provisions echo three of the CRC's general principles, in terms of non-discrimination (Article 2), children's best interests (Article 3) and children's views (Article 12).

Given the above, the implications for research are considerable. Numerous authors have articulated what a rights-based approach could be for childhood research (e.g. Bessell 2016; Collins 2012; Lundy and McEvoy 2012; special issue of *Children's Geographies* 2009 7(4)). Beazley and colleagues (2009) write of children's right to be researched properly, which they summarise into four elements based on certain CRC articles: children should be research participants; methods should make it easy for children to express their experiences, views and opinions; children should be protected from harms that could result from research participation; and the quality of research should be ensured, in terms of methods, analysis, management and supervision. Others go further, such as Lundy and colleagues. Rights-based research requires stepping back from conventional research approaches, across the disciplines, to ensure human rights standards are applied to all aspects of research – from design, to fieldwork, to ethics. Lundy and McEvoy (2012) elaborate on changes that must be made. Research questions must be framed in the language of rights. The research itself must build rights-holders' capacity to claim their rights and duty-bearers to fulfil their obligations. The former requires support for children to form their views, so they can have informed and formed views when they are involved in research. Children need to participate in the various elements of research fieldwork, analysis and dissemination. Just as human rights must be considered holistically, so must their application to research. As suggested in the introduction, a particular

emphasis of such rights-based approaches – and the biggest challenge perceived to conventional research – is the participation of children.<sup>4</sup>

The sections below pick up three issues related to participation, of particular salience to research with children with disabilities.

## Communication and ‘voice’

The Conventions give strong grounding for children’s participation in research and particularly for respect for children’s own views on matters that affect them. This has precipitated an enthusiasm for children to be participants in research, as important contributors to answering research questions about their lives, experiences, attitudes and views. It has encouraged researchers to develop and use a variety of ‘participative’ or ‘creative’ methods. While largely but not solely qualitative, such methods range from photo tours, where children are encouraged to take pictures with cameras or other devices, to story-telling and puppets, to drawing and other arts-based activities (e.g. see Aldridge 2015; Johnson et al. 2014; Lyons and Roulstone 2017; Tisdall et al. 2009). Such methods are argued as more effectively and ethically involving children in research, in comparison to relying solely on ‘traditional’ research methods such as filling in tickboxes on a quantitative self-report survey or face-to-face interviews. Kesby, for example, argues that such methods create better knowledge: they will ‘access and valorize previously neglected knowledge and provide more nuanced understandings of complex, social phenomena’ (2000: 423). Better knowledge in turn will create better data, better decision-making and best results. These methods create better knowledge, because they are ‘in tune with children’s ways of seeing and relating to the world’ (Thomas and O’Kane 1998: 337). This also makes them more ethical, argue Thomas and O’Kane (1998), as they give children more control over the research process. Participatory methods are characterised as inclusive, in at least two ways. First, often children have choice in methods, so that if one method were not preferred or suitable, another one is used (e.g. see Clark and Moss 2001). Thus a wider range of children can be involved, who have different communication preferences. Second, the participatory methods can recognise communication in addition to or instead of words, the latter of which are so often relied upon within social science research methods (Komulainen 2007). Such participatory methods have been widely used in childhood research and have been specifically used in research with children with disabilities (e.g. Brady et al. 2012; Raibee et al. 2005).

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<sup>4</sup> For example, see <https://www.qub.ac.uk/research-centres/CentreforChildrensRights/ChildrensRights-BasedResearch/ARights-BasedApproachtoChildrensParticipationinResearch/> (accessed 4.5.17)

This inclusivity fits well with the interpretation of children's participation rights by the UN Committee on the Rights of the Child. The Committee's General Comment on Early Childhood, for example, emphasises that adults need to demonstrate patience and creativity, adapting to the interests, understanding levels and preferred ways of communication with young children (2005: para 14). It fits with a disability rights paradigm, which recognises impairments but argues that society creates the disability through oppression, discrimination and barriers (Tisdall 2012; Watson 2012). It is for the research to change, rather than the individual with the impairment. The emphasis then becomes the researcher's responsibility to find ways for children to participate, rather than excluding children because they do not neatly fit into the researcher's set protocols. Children's involvement as research participants has often been celebrated as giving 'voice' to children and thus recognising their rights to participate. It has resulted in numerous publications that contain lists of quotations from children and other productions of and from children such as podcasts, videos and artistic creations. Projects abound that are 'child-led', which typically means that children work on all research stages – from research questions to fieldwork to analysis and subsequent dissemination (Michail and Kellett 2015; Spalding 2011). There is an enthusiasm, therefore, amongst committed adult researchers to expanding traditional methods to facilitate children's participation and to ensure their voices are heard.

While maintaining the commitment, there is a growing recognition in the literature that the emancipatory claims for participatory methods and presenting the 'voice' of the child are not inevitably met. Simply using an art-based method, such as drawing, or taking a photo tour with a child, does not necessarily mean that the child has more control over the research process, that the child enjoys participating, or that participatory methods will meet different children's communication needs. For example, children can feel pressured about drawing, particularly as they get older and if they are in a school setting; they can feel their drawing is judged by external standards, that they are not a 'good' at drawing, or that they must follow conventions on how they should depict something (Einarsdóttir et al. 2009; Tisdall 2015). Participatory methods are often reduced to text for the analysis, as children are encouraged to talk or write about what pictures they took or what art they created. This helps check the researcher's understanding of the data and thus interpretation. But it privileges text and crowds out the other communication methods. The claims to present children's 'voice' have also been recognised as problematic. First, the use of a singular voice belies the diversity of children, who may not have a homogenous view or experience but instead considerable heterogeneity. Second, Komulainen (2007) points out that voice privileges certain forms of communication, which may not be available for particular disabled children. While voice can be put into inverted commas, to indicate it is not to be understood narrowly but widely,



such phrases feed into discourses that exclude disabled children. Third, 'voice' presumes that there is a fixed perspective, which a researcher can access and present. Whether we take a modernist or post-modern view, this expectation is unrealistic. We can expect any person's view to change over time, by context, and by how it is elicited (for discussion, see Gallacher and Gallagher 2008; James 2007). Lastly, research can be presented as the voice of the child or children without acknowledging the researcher's role. For example, reports abound that have been written by adult researchers, who have selected the quotations as excerpts from transcripts, arranged the quotations within a narrative, and presented both analysis and recommendations. The adult's role can be equally pervasive, in editing of videos or art exhibitions. Children may have limited to no involvement in any of these analytical and presentational processes.<sup>5</sup> The researcher's role may well have considerable merit, in terms of technical expertise, paid time and dedication. What is more problematic is that the co-production, the contribution of both the researcher and the children in different or similar ways, is not acknowledged reflectively and reflexively (see Gallagher 2008).

Thus, the CRC gave considerable impetus to recognising the rights of children to participate and has been picked up with enthusiasm by numerous researchers. As practice and experiences accumulate, more critical perspectives are emerging that can hone how such research is designed and carried out. For example, we can recognise that many research participants can enjoy 'participatory' methods and that they may be very good methods to answer particular research questions but such methods do not inevitably create better knowledge nor are they inherently more ethical and more inclusive. Any method, whether labelled participatory or not, will include and exclude certain people. The question then becomes about making considered decisions in light of this. The emancipatory claims of such research can be more thoughtfully tested, to consider the different possibilities for children's involvement in research. Arguably, we need far more research that is based on children's own priorities and is undertaken to their own design. But research can also be productive that is not 'child-led' but respectfully engages children as participants and advisers, and recognises the respective roles of those involved. A more critical appraisal and judicious consideration of robust research will only strengthen its quality – and be more respectful of children's rights to participate.

## Competence and capacity

The CRC and CRPD have established a place for children's participation, where it may not have existed before in legislation nor in practice. Whereas previously children may not have been judged

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<sup>5</sup> To note that there are a growing number of research projects that do involve children more deeply in research production, including analysis and presentation.

as competent enough to be involved in making a decision, and thus lacking the capacity to participate, Article 12(1) of the CRC and Article 7(3) of the CRPD assert that they have the right to express their views freely in all matters affecting them.

This right is to be interpreted generously, according to the CRC Committee: a child should be presumed to have the capacity to form his or her own view and ‘it is not up to the child to first prove his or her capacity’ (UNCRC 2009: para 20); a child need not have comprehensive knowledge to be considered capable of having a view (UNCRC 2009: para 21); there is no age limit on the rights of the child to express his or her views (UNCRC 2009: para 21); and the right should be applied to younger as well as older children (UNCRC 2005). Thus a child’s capacity is relevant to their participation rights but should be defined generously. Further, children’s capacity should be supported: information is a precondition to a child’s ‘clarified view’ (UNCRC 2009: para 25) and an identified right of the CRC. Age-appropriate assistance should be provided for children, to facilitate their participation (Article 7, CRPD and Article 23, CRC). Thus children’s capacity is recognised as not necessarily set but something that can develop and change with further skills, experience and knowledge – and children have the right to be supported in this way. The development of children’s capacities is explicitly addressed in Article 5 of the CRC, which recognises the ‘evolving capacities of the child’ as balancing parental rights and responsibilities to direct and guide children with the increasing autonomy of children (see Lansdown 2005 for analysis).

This ‘place’ for children’s participation, where it may not have been respected before, has numerous implications for research. First, it has encouraged a host of research studies to be funded, from non-governmental organisations seeking to present research of children’s views to influence services or policy, to statutory bodies needing children’s views in order to evaluate or change their services or policy. Second, it has increased children’s inclusion as research participants, as well as other research roles. Third, it asks questions about the informational as well as other support and assistance to participate in research. As Lundy and McEvoy (2012) point out, this can be challenging to certain research designs and expectations, where providing information before research participation can be considered leading and thus biasing the research. A rights based approach has widened the depth and breadth of children’s participation.

However, there are caveats to this progressive depiction. As more extensively discussed in Tisdall (forthcoming), capacity and competency are terms frequently used in the literature and policy around children’s participation but rarely with definition. Children are assumed to have ‘evolving capacities’ while adults do not; the result is children having less responsibilities than adults but more protection (Lansdown 2005: xiii). While the General Comment on Article 12 does advocate a wide interpretation of children’s capacity, Article 12 and thus the General Comment allows for some

children to be considered *insufficiently* mature and *not* capable of having an informed view and thus not able to exercise Article 12 (CRC) or Article 7(3) (CRPD).

This can play out problematically in research, in at least three ways. First, children and particularly disabled children can still be excluded from research. While participation rights have encouraged researchers to look to their own competence to facilitate children's research participation, rather than excluding children as incompetent, this only goes so far. Children are casually discriminated against by age, which would be unacceptable for other equalities issues such as race, gender or religion. Consider, for example, the amount of public investment in surveys that only include those aged 16 or 18 and above, despite the surveys addressing issues of considerable import to children – such as crime, poverty, and quality of life. If this is true for children generally, it is even more true for younger children. Some research methods literature, for example, continues to assert that questionnaires are best not used with children under the age of 8 (e.g. Bell 2007). Yet other studies show that, with the appropriate information and methods, children at much younger ages can contribute meaningfully to such questions and issues (e.g. see Greig et al. 2007). The details of the original studies are not always considered and such references are regularly used as a quick way to explain why younger children are not included. Disabled children risk exclusion as well. The support to ensure their participation can be considered too expensive or time-consuming and this can justify their exclusion (to recognise that a research team may well do this reluctantly but the fact is that the justification is accepted). Thus, the 'place' for children in research has arguably expanded due to recognizing participation rights but certain exclusions are still easily justified, on the basis of the children not being competent or not having the capacity to participate, without extensive evidence nor consideration of alternatives.

Second, because such exclusion is recognised by a host of committed researchers, specialist projects are developed, where researchers ensure the resources and methods are there to include disabled children. While immensely worthwhile in themselves, there remains the risks that research with young disabled children is not mainstreamed into research with children more generally, just as research with children is not necessarily mainstreamed into research with adults. It also can lead to projects focusing on issues related to disability, rather than the myriad of issues that may be important to children who have a disability. This has been raised by disabled children themselves (Barnardo's Scotland et al. 2011; McMellon and Morton 2014), who do not always want the focus to be on their disability and who want to have their views considered on other issues of relevance to them.

Third, ethical practices remain unsettled about children's capacity to agree to participate in their own right within research. It would be conventional within childhood research that children's

agreement to participate is paramount, if the child were the one taking part. Thus if a child did not want to participate, or withdrew their participation during the research, this must be respected by the researchers. What is less decided is parents' (or other legal guardians') role in agreeing or not to the child participating. In some arenas, a parent's consent is required; thus leading to the potential that a competent child wants to participate in a project but the parent does not agree. Typically the parent's view prevails.

Part of this problem lies with the construction of 'informed consent'. The practical problems of achieving informed consent are well-rehearsed in the literature (e.g. see Alderson and Morrow 2011). It is also more conceptual, as informed consent is set in a contractual framework<sup>6</sup> – as exemplified by the request for signatures to demonstrate agreement. A contract presumes sufficient information on both sides, to make a contract valid. Yet certain types of research such as ethnographies or action research can begin with very open agendas and lead to unexpected findings and outputs; whether information can be sufficiently explained to meet the above criteria is difficult. Should contract terms not be met, the injured party should have legal redress; the articulation of this within research governance is still in its infancy. A contractual framework is based on legal capacity to agree and sufficient competence to do so. Given the above problems, other frames may in fact be more ethical – such as trust, professionalism and professional accountability – and indeed human rights.

Overall, then, children's participation rights have expanded their place in research: to be involved as participants as well as other roles and to decide on their own behalf if they want to participate and to continue to do so. However, the participation rights are highly qualified. Article 12(1) and Article 7(3) are far from 'self-determination'. Capacity and competency are loosely defined concepts within the field, which are easily used to exclude as well as include children in research. It is questionable whether they are useful concepts to guide children's participation. It is increasingly realised that all people have evolving capacities and that competence is situational and relational rather than intrinsic and individual (Tisdall forthcoming).

## Research ethics

If informed consent remains a major discussion point in the literature, it is not the only one that childhood research considers. For those located within 'childhood studies' and 'children's rights studies', research ethics have long been an obsession and the subject of considerable attention, debate and concern. Trends can be picked out in terms of the discussions. First, research ethics should permeate all aspects of the research, from its original design to its fieldwork and analysis, to

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<sup>6</sup> This section draws on Scottish contract law (e.g. MacQueen and Thomson 2016).

its dissemination. Second, research ethics are more than meeting regulatory requirements; they require a deep consideration of principles and ongoing reflective practice. Third, research ethics are still largely what adults think are good for children, rather than having extensive involvement from children in deciding ethical practice, judging it or holding researchers to account. The first two trends are in line with a human rights approach, in taking a holistic view and respecting the human dignity of those involved in research. The third remains an outstanding issue, given children's participation rights as internationally agreed.

Research ethics for children's involvement as research participants have become increasingly established on certain issues: what can be considered 'default' positions such as caveats on confidentiality (typically, a researcher is required to have a process for reporting any concerns about child abuse) and protecting anonymity (typically, a researcher would not use a child's name when reporting on the research). As children become involved as more than participants in research projects, some of these positions are being questioned or raising new issues.

One is the ownership of research and who benefits thereof. As more research projects are involving children in roles such as advisers, researchers and more, issues arise about due recognition. Frequently, adults are paid to undertake research studies. Should children be paid if they take on similar roles? Replacement costs for lost wages is commonplace, for children, but that is not the same as paid employment as researchers. In Europe, law prohibits most paid employment for children under the age of 15.<sup>7</sup> Interpretations of health and safety requirements can preclude children being in certain institutional environments, such as Universities. Questions arise about the position, respect and power relationships of such involvement. Who owns the data and the rights of authorship? Research is frequently published with the names of the adult researchers as authors or due recognition of the researchers. This public naming can be problematic given the default positions of anonymising children who are involved in research. A convention is growing that children's first names will be used, following mutual agreement, if they have been involved in such co-production. But does this fully and long-term recognise their intellectual property? Such issues extend into the 'knowledge exchange' elements of the research, where the research engages with other stakeholders, typically to maximise research impact. Again, if there are widespread concerns about using children's photographs and children's digital footprints more generally, the ethical sensitivities of involving children in knowledge exchange -- and balancing their participation rights with concerns about protection -- grow. There are outstanding issues, of continued debate in the literature and in practice, about how to balance agreements now -- which children may have been

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<sup>7</sup> Council Directive 94/33/EC of 22 June 1994 on the protection of young people at work, <http://eur-lex.europa.eu/legal-content/EN/ALL/?uri=CELEX:31994L0033> (accessed 25.8.17).

well informed about and given their agreement – with the longevity, searchability and replicability now possible in digital technology. Will they be as content to have their outputs at age 5 readily seen by others when they are in their teens or older?

The literature on childhood research, generally and specifically with younger children and with disabled children, has much to contribute to ethics discussions more widely. Its holistic and questioning approach is well aligned with the breadth of human rights and its value base in human dignity and respect. Increased involvement of children has raised new challenges, particularly in balancing the protective assumptions of research ethics with children's participation rights – and, further, ownership and intellectual property.

## Conclusion

The increased recognition of children's human rights, and particularly their participation rights, has influenced certain research arenas. More projects are involving children as research participants, as well as other roles as advisers, consultants, peer researchers and projects that are 'child-led'. There have been leading projects in this regard of disabled children and young children – and combinations thereof. There has been accompanying interest in methods to involve children in these ways, with the proliferation of methods labelled 'participative' and 'creative' that seek to tap into ways that children do and want to communicate, sensitively and ethically. There has been a widening of who is considerable capable and competent enough to participate in various methods, on particular topics, and in various ways (McNamee and Seymour 2012).

This progressive depiction is heartening, for those committed to children's human rights. It is not necessarily so embedded that its continuation will be guaranteed; certainly, with the 'innovation' of children's participation now past, funding may well not prioritise such projects in times of financial austerity and enhanced research competition. It is not necessarily mainstreamed into research more generally: while studies might be queried about why gender has not been considered and incorporated into the research design, the involvement in children would rarely be expected (despite children being a notable proportion of any country's population).<sup>8</sup> Just as human rights more generally can feel threatened by other worldwide priorities and pressures, so can children's participation in research.

As experiences of children's participation in research have broadened and deepened, so has an 'insiders' critique that seeks to interrogate some of the practices and their underlining assumptions. This book's focus – young disabled children – provides a very productive lens to do so.

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<sup>8</sup> Ranging from 14% to 48% of a country's population, aged 0-14 estimated as of 2017. <http://data.worldbank.org/indicator/SP.POP.0014.TO.ZS> (accessed 4.5.17)

It leads to questioning the emancipatory claims of children's participation. It, for example, allows us to question the inclusivity and exclusivity of research methods (whether participatory, creative or traditional), the continued preoccupations with children's competency and capacity, and ethical issues that arise when we are involved in forms of co-production and child-led research in terms of anonymity, authorship and ownership.

Despite the revolutionary claims for children's participation rights within the CRC, and repeated in the CRPD, this chapter demonstrates that they are highly qualified rights, with adult judgements of children's capacity and competency still determining children's inclusion or exclusion. Best interest concerns can further trump children's participation, particularly when only children are seen as having evolving capacities and requiring protection. It is timely to recognise that the CRC and CRPD are minimum thresholds, subject to the political consensus at the time. There are opportunities to extend children's participation rights. What if we decided that ideas of children's competency and capacity were not the relevant criteria to determine research participation and research ethics, and particularly not ones that saw competence and capacity as individually set characteristics but relational and situational? If we take co-production seriously, how does this challenge certain established ideas of how to do and judge research, about protective aspects of research ethics in light of ownership and contribution? If we recognise that the exclusion of young disabled children from most research, and its treatment as a niche specialism, as a form of discrimination, how would that change research investments from funders -- to influence not only children's research but research more generally? Human rights remains a radical framework that continues to challenge research practice, asking us to go further in truly recognising and respecting children's human dignity in research governance, practice and ethics.

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